A longitudinal, qualitative study exploring sustained adherence to a hand exercise programme for Rheumatoid Arthritis evaluated in the SARAH Trial

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Abstract

Purpose

This study explores the experience of participants taking part in a hand exercise programme for people with rheumatoid arthritis with a focus on adherence. The exercise programme was tested in a randomised controlled trial. This parallel qualitative study will inform future implementation into clinical practice.

Method

Twenty-seven semi-structured interviews from 14 participants were undertaken at 2 time points (4 and 12 months after randomisation). We collected data of participants' experiences over time. This was guided by an interview schedule. Interview data were analysed using interpretative phenomenological analysis which is informed by phenomenological and hermeneutic theory. We recruited participants from National Health Service rheumatology and therapy departments.

Results

At 4 months, 11/14 participants reported continuing with the exercises. By 12 months, 7/13 participants still reported exercising. The ability to establish a routine determined whether participants adhered to the exercise programme. This was sometimes influenced by practical issues. We also identified facilitators and barriers to regular exercise in the themes of – the therapeutic encounter, perceived benefit of exercises, attitude of mind, confidence and unpredictability.

Conclusions

Establishing a routine was an important step towards participants being able to exercise independently. Therapists provided participants with skills to continue to exercise while dealing with changes in symptoms and schedules. Potential barriers to long term exercise

adherence need to be taken into account and addressed for successful implementation of this programme.

Key words: Rheumatoid arthritis, exercises, adherence, patient interviews

INTRODUCTION

The primary treatment of rheumatoid arthritis (RA) is pharmacological but guidelines advocate exercise as supplementary treatment for all stages of RA (1, 2). Exercise has been shown to improve muscle strength and endurance without impacting on pain or disease activity(3). Adherence is integral to achieving long term benefits of exercise (4) but helping patients with RA to exercise regularly and over a prolonged time period is challenging (5). Exercise adherence is a complex health behaviour and no single factor explains how or why some patients can adhere to an exercise programme and others not (6). Possible influences include positive re-enforcement from clinicians and carers/peers, positive experiences of past exercise participation, positive attitudes and beliefs toward exercises, confidence in self-management ability, positive perceptions of health status, fewer comorbidities and good symptom control (5-8). However, both patients and clinicians report concerns that exercise will exacerbate symptoms, and uncertainty about the optimal type or dose of exercises and who should advise patients about exercising (9, 10).

The SARAH (Strengthening And stretching for Rheumatoid Arthritis of the Hand) randomised controlled trial (RCT) evaluated hand exercises in 490 people with hand RA and demonstrated that a progressive, individually tailored strengthening and stretching exercise programme was an effective and cost-effective adjunct to drug regimens (11). Seventeen

National Health Service (NHS) Trusts took part in the SARAH Trial. Ensuring that participants carried out daily exercises was a key element of the intervention and we utilised evidence based strategies to maximise adherence (12). The aim of this parallel, interview study explored the trial participants' experiences of the exercise programme and, in particular, how successfully they adhered to the programme over time. We chose a longitudinal study design to investigate the transition from supervised exercise to independent exercise, seeking insight into facilitators and barriers to exercise and changes in symptoms/experience over time. Understanding this process is a crucial part of developing an effective implementation strategy to facilitate the uptake of the SARAH exercise programme into clinical practice.

PATIENTS AND METHODS

Participants

Participants were 14 people who had been randomised to the hand exercise programme being evaluated in a pragmatic RCT (SARAH RCT ISRCTN-89936343). Details of the trial and intervention are reported elsewhere (11, 13, 14) but, briefly, participants were adults (≥18 years) diagnosed with RA reporting pain and dysfunction of hands and who were either not on medication or on a stable drug regime for three months or more.

The intervention comprised progressive strengthening and stretching exercises. Resistance bands, balls and putty were provided and the intention was for exercises to be completed daily for at least the duration of the study (14). Following an initial assessment, the programme was supervised by an occupational therapist or physiotherapist during five face to face sessions spaced over 12 weeks. After this, participants were expected to exercise independently. The exercises were individually tailored and participants were taught how to

progress and modify them (e.g. if symptoms changed). We used behavioural techniques to encourage adherence including an exercise contract with goal setting and agreement on a place and time to do the exercises. We used an educational behavioural model as it can be helpful with adhering to joint protection advice (15). The behavioural components of the intervention utilised strategies published in the the Improving Health: Changing Behaviour NHS Health Trainer Handbook. This is based on the Health Belief Model and are evidenced based strategies to plan and implement behavioural change (12, 16, 17). The therapist also assessed any facilitators and barriers to exercise promoting discussion with each participant. Participants were asked to keep a paper daily diary sheet to record the exercises completed and to note any difficulties, problems or reasons for not doing the exercises. Exercises were primarily intended to be completed in one sitting but therapists were able to modify this if needed as long as each exercise was completed daily.

The participants were sampled purposively from 4 of the 17 participating NHS Trusts local to the trial co-ordinating centre for pragmatic reasons of time and cost. Participants were recruited to the interview study after completion of the supervised component of the intervention (a minimum of four months after randomisation). We used responses to the question “How much benefit have you gained from the advice or treatment you have received as part of the SARAH Trial?”collected at the 4 month follow up appointment, to identify participants who felt they had benefited and not benefited from the exercises in order to gain a range of experiences. We interviewed 10 participants reporting benefit at which point data saturation was reached. However from our local areas only 4 participants reported that they did not benefit from the intervention. Participants were given verbal and written information describing the processes of confidentiality, anonymity and analysis by

the research team. All gave written consent on the understanding that their participation was voluntary and they could withdraw at any time without prejudice. Interviewing people about health conditions has the potential to elicit strong emotions. We put safeguarding procedures in place to protect interviewees, by referring back to appropriate healthcare services, as well as researchers by following a lone worker policy. The Oxford C Multi-centre Research Ethics Committee provided ethical approval on 10/06/2008, ref: 08/H060/47.

Data collection

We interviewed 14 participants at four months, and 13 at twelve months (one participant declined a second interview for personal reasons) at a venue chosen by the participant (home [*n*=12], work [*n*=2]). Interviews lasted from 26 to 78 minutes.

We used a semi-structured interview schedule (Box 1) for the interviews at both time points and these were developed during a pilot phase (not reported). The second interview schedule focused on the time since the first interview. However changes were made to the schedule as the study progressed which is in line with an interpretative phenomenological approach. The first interview transcript and research notes were reviewed to identify topics for further exploration with each participant. Two researchers (VN and EW) carried out the interviews which were audio-recorded, transcribed verbatim, anonymised and checked by the interviewer for accuracy. Participants selected or were allocated a pseudonym to protect anonymity. Researcher notes, written immediately after the interviews, promoted further reflexivity across cases and time points.

Participants provided demographic and descriptive data including years since RA diagnosis, medication use, hand function (Michigan Hand Outcome Questionnaire (MHQ) (18)) and pain ratings. Information about attendance at exercise sessions was provided by the treating therapists.

Insert Box 1 about here

Analysis

Two researchers (VN, EW) with backgrounds in physiotherapy and qualitative work on rehabilitation trials, analysed the data using methods of Interpretative Phenomenological Analysis (IPA) (19). IPA attempts to explore a phenomenon from the interviewee's perspective and using a hermeneutic approach, the perceptions and meanings they ascribe to it. This made it a suitable approach to fulfil the study aims. IPA recognizes the researcher's role in interpreting this experience and is a useful approach in health research (20). Transcripts were read and reread then initial codes were developed. Initial coding was done line by line. We then grouped patterns of codes into themes working iteratively from the data and across cases to develop superordinate themes. We explored relationships between themes which influenced adherence. Particular attention was paid to any differences between the emergent themes from the 1st and 2nd interviews as we were interested in how participants' experiences changed over time. Quotes were selected to illustrate themes. NVivo software (QSR International Pty Ltd. Version 10, 2012) was used to organize and share coding between data collectors. A third experienced qualitative researcher (FT) reviewed the coding to ensure that themes fitted the data and contributed to the analysis.

RESULTS

Participants varied in their hand function, age, years since diagnosis(ysd), and were taking a variety of different medications. There was a mix of gender, educational background, employment status but all were white in ethnic origin. Interviewee characteristics were similar to the main trial and descriptive data are provided in Table 1. Eleven participants reported exercising at 4 months and seven at 12 months. Reasons for discontinuing with the exercises are given in Table 2.

Insert table 1 and 2 about here

Superordinate themes “Practical Issues” and “Facilitators and barriers”were further abstracted into an overaching theme “Establishing a routine”

Establishing a routine

The overarching theme of ‘establishing a routine’ underpinned sustained exercise adherence (see figure 1). Some participants described the end point of establishing a routine as exercise becoming a habit suggesting that this was when the new behaviours were embedded into their life.

> Introducing it into the routine and being able to manage time was probably the key difficulty . . . this is an activity that is now inbred within your general activity of a day and it becoming a habit is then just something that now evolves through naturally, and I think that’s a key difference for me. (Sadler 1st interview, age 44, 4ysd)

The themes presented below represent the different factors involved in the process of establishing a routine.

Insert fig 1 about here

Practical Issues

Fitting exercise into life and feeling able to modifying the exercises were important practical issues integral to establishing a routine. Some participants took the routine on board immediately whereas others needed to adapt the programme. Participants found innovative ways of fitting exercise into their lives, either by 'trial and error' or slotting exercises into pre-existing routines.

> I always believe in getting things done early of a morning. I've always done that, so it was the best way of doing it. (Joe 1st interview, age 61, 4ysd)

> . . . I put the sheet and everything on my desk so it was there and I could see it, so therefore I would remember it and I kept these in the playroom as well, so when I sat down at the table with [Son] say to do his homework, then it would be there and then I could carry on. (Samantha 1st interview, age 49, 4.5ysd)

> It's quiet. There's nobody else there. It's peaceful and I often whip through them and I do my spinal exercises then as well. (Kate 1st interview, age 51, 2.5ysd)

All participants mentioned modifying the exercises, but most made modifications during the unsupervised period by modifying the type of exercise or the time and place that they performed them. Changes had been suggested by therapists or the participant made changes in response to their symptoms or lifestyle. Most commonly, this was to split the

exercises up into two sessions, or to spread them thoughout the day. Identifying the most convenient times of day to use equipment to ensure exercises could be done was important.

> What I do is sometimes at work I'll do them [exercises] as well, so if I'm on the phone . . . I often use my strength [exercise] one then, so you do adapt and you change things. (Kate 1st interview, age 51, 2.5ysd)

At twelve months half the participants reported exercising and most of these spoke of further modifications.

> … I don't count how many I do now, I just do them through the day and at the traffic lights . . . and people look at me (laughs) and it's much easier just to do them during the day and just use them as part of a routine. I couldn't sit down and spend half an hour doing them, it doesn't work. (Alice 2nd interview, age 49, 5ysd)

Facilitators and Barriers to establishing a routine

Besides the practical aspects of establishing a routine, 5 facilitators and barriers to this process were identified.

The Therapeutic Encounter

Therapists were instrumental in helping participants to establish a routine. Participants valued the contact with the therapist and described them as motivational, providing useful feedback, helpful in fostering a positive mind-set and in improving confidence and self-efficacy. The 'tailor-making' of exercises rather than a 'one size fits all' programme was particularly appreciated. Behavioural techniques used by therapists including exercise contracts, goal setting and diary sheets helped participants to establish a routine.

> They're all sort of modified to suit. You know, it wasn't that you had this goal that if you didn't achieve X amount of exercises you couldn't carry on. It was all how much I could do, so once I found out I was quite excited because I thought it could only help me. (Alice 1st interview, age 49, 5ysd)

Some participants felt more contact with the therapist would have been useful and that exercising independently was harder to maintain. This was most apparent at 12 months when participants were no longer seeing their therapist.

Perceived benefits of exercise

Benefits were described as either real or potential. Experiencing improvements in symptoms and physical abilities motivated participants to exercise.

> Using the secateurs and also just to pull the stubborn weeds out. You can probably grip those better and pull them out easier and lifting certain things with my hands and so for example, the container off the lawnmower. (Samantha 1st interview, age 49, 4.5ysd)

Physical benefits were reported at the first interview but it was at the second interview that the psychological benefit was more apparent. Participants spoke of increased confidence along with a sense of empowerment and optimism in slowing the disease progress and maintaining function.

> …when I was first diagnosed with it I didn't have any control over it whatsoever, whereas I'm actually doing something that's practical that might help … if that is in my hands to make that change I can do that. If it's not in my hands I'm helpless and therefore that's actually quite a difficult place to be, so the project for me I think has

been really quite valuable because it's empowered me. (Kate 2nd interview, age 51, 2.5ysd)

I'm looking to introduce changes to the way I act today in order to have a better long-term prognosis and I definitely see that this [exercise] is something that's going to lead me in that direction.
(Sadler 1st interview, age 44, 4ysd)

If participants did not expect any benefit, this was a barrier to exercising. Two participants felt that their hands were 'too good' to benefit, and one of these discontinued treatment after three sessions.

Attitude of mind

A positive attitude of mind was important to adherence and helping the exercises to work. Participants described positive 'mind-sets' which included being; motivated, committed, 'willing to put in the effort', self-disciplined, and responsible for your health. A positive attitude was considered instrumental in helping the exercises to work.

I think it's attitude of mind and commitment – the wanting to do it… (Lucy 1st interview, age 64, 21ysd)

Participants suggested attitudes which may stop people exercising including viewing the exercises as tricky or an effort, or finding it 'easier not to do them.' Participants felt people could be de-motivated if they did not have a good enough reason to engage with the programme, were unrealistic about the amount of effort needed or wanted instant results.

> Well, some might not keep to it you see … they might do it for a few days and then say, 'Oh well that's it', or if they haven't got a good enough reason to do it, you know? (Harry 1st interview, age 77, 23ysd)

Confidence

Some participants described the way they had taken control and integrated the exercises into their lives in a confident flexible way. They were able to modify their exercise independently and described ownership of the exercise programme and how this aided adherence.

> . . I was doing the exercises more fluently and I feel quite confident doing them and just generally with handling things and just better hand function I think . . . but to actually feel that you can be doing something that's active and positive and proactive for yourself then that in itself. You can't put a price on that . . .(Alice 1st interview, age 49, 5ysd)

Unpredictability

As time progressed, more participants described events that interfered with exercise adherence. This included dealing with the stage of their disease, changes in medication, fluctuating symptoms, flare ups or life in general.

> It does seem to be more of a roller coaster, I don't seem to have a nice even plateau. It does seem to be like, 'Oh god the steroid injection's kicked in,' and then the other tablets seem to hold it at bay for a week, a fortnight, maybe three weeks and then we start on the downward slope again. One of the Methotrexate now will start, helping to keep me on the plateau, . . . At the moment it does seem to have been

> maybe a week a fortnight of things being relatively level and then we seem to take a dip, then we start climbing up again and then I'm feeling 'Weyhey, I'm great.' And then we've got whoosh! Back down again. (Lizzy 2nd interview, age 59, 8months since diagnosis)

Most adapted their exercises in response to changing symptoms and some used exercise to alleviate these. However, for others, 'day to day living' was enough during a flare up and they could not exercise during this time.

> It's like someone just pulls the plug out of your motor and it stops. (Mark 1st interview, age 58, 15ysd)

Being busy or having competing priorities also made exercising difficult.

> You know, you think 'I've got this appointment,' or 'I've got that to do.' You know, 'I'll do it later,' and then you forget. (Sally 1st interview, age 63, 27ysd)

DISCUSSION

We explored the experiences of participants undertaking a hand exercise programme that has proven to be clinically and cost effective (11).

We were particularly interested in factors influencing successful transition from a supervised to self-managed exercise programme. As time from the therapist-supervised sessions elapsed, it became more difficult to maintain exercise adherence. Adherence with an exercise programme is a complex behaviour with no single factor able to explain adherence behaviour (6) and we also identified a range of factors, but, they were all linked

to the concept of establishing a routine. Establishing a routine during the supervised period was essential if participants were to continue to exercise. This was influenced by practical issues and other facilitators and barriers.

Establishing a routine depended on participants being able to fit the exercises into their schedule. People with RA often need to make changes to adapt to the demands of their condition (21, 22). Incorporating exercises into this potentially shifting landscape is challenging but clearly, as demonstrated by some of our participants, not insurmountable. Previous work has established individual tailoring of programmes is helpful (23, 24), and we add that empowering participants with the confidence to self-modify their programme was a critical skill to cope with changes in their lives or symptoms. Interviewees spoke more about the psychological benefits such as increased confidence at twelve months rather than more physical improvements suggesting it takes time build confidence. Those that successfully mastered this element of the programme were more likely to continue to exercise despite having no contact with a therapist for up to 9 months.

Our findings resonate with the theory of self-determination which has been used to explain adherence to physical activity programmes by patients with RA (25, 26) and healthy individuals (27). This theory proposes that motivation to carry out behaviours can be internal or external (28). Internally motivated individuals can regulate their own behaviour and take ownership of goals and is generally associated with better outcomes. A positive mind set towards exercising, putting in effort, being in control and taking ownership of the programme were related to adherence with the programme and could be likened to internal motivation. Perceived benefit also motivated some participants but the opposite was also observed. Those who felt they had little to gain were unlikely to exercise.

Externally motivated individuals show greater reliance on coercive methods such as rewards or support from others however, these factors can be used to bolster internal motivation (28). External motivation, provided through interaction with the therapist, was an important strategy to encourage exercise which was successful for some participants but not all in achieving long term adherence. One reason for this may be that the exercises had to be implemented against a backdrop of unpredictability. The struggles faced by patients with RA to manage the unpredictability of symptoms and to deal with flare ups is well documented (29).

Some participants who successfully established a routine talked about the exercises becoming a habit. The concept of exercise becoming a habit has also been associated with long term adherence to exercise referral schemes (30). When a behaviour becomes habitual, it is automatic and relies less on conscious thought or intention to perform it (31). New behaviours require thought and attention to perfom but as behaviours are repeated they achieve a degree of automaticity (31). For some participants who successfully established a routine and, thus, repeatedly performed the exercises, the exercises became a habit. Although, it is not the actual exercises per se that become habitual, as the individiual needs to pay attention while exercising, but it is the decision to exercise that becomes the habit (31). The decision to exercise becomes automatic and not dependent on reflective factors such as intentions or beliefs (32). An important aspect of developing habitual behaviours is that they are performed in a stable context (32). This maybe a reason that more participants did not report habituation of their exercises as RA represents an unstable context when dealing with fluctuating symptoms.

Clinical implications

In order to maximize the potential clinical benefits of the the SARAH exercise programme, therapists should work with patients to establish a routine during the supervised sessions with the expectation that they will be carried out long term. Therapists can successfully encourage adherence using strategies such as contracting goal setting, exercise diaries and joint problem solving, and these are appreciated by patients. Therapists should identify barriers to exercising and work with patients to overcome them. Patients need to be confident to adapt their exercises in response to changing symptoms and life events in order to facilitate long term adherance. Symptoms experienced by participants limited their ability to exercise, so effective symptom management is potentially important when promoting exercise adherence.

Many participants would have valued continued support, advice and encouragement. Providing primary and secondary care services with simple guidance on ways to reinforce exercise adherence, and/or enabling referral to therapy services for review may be useful.

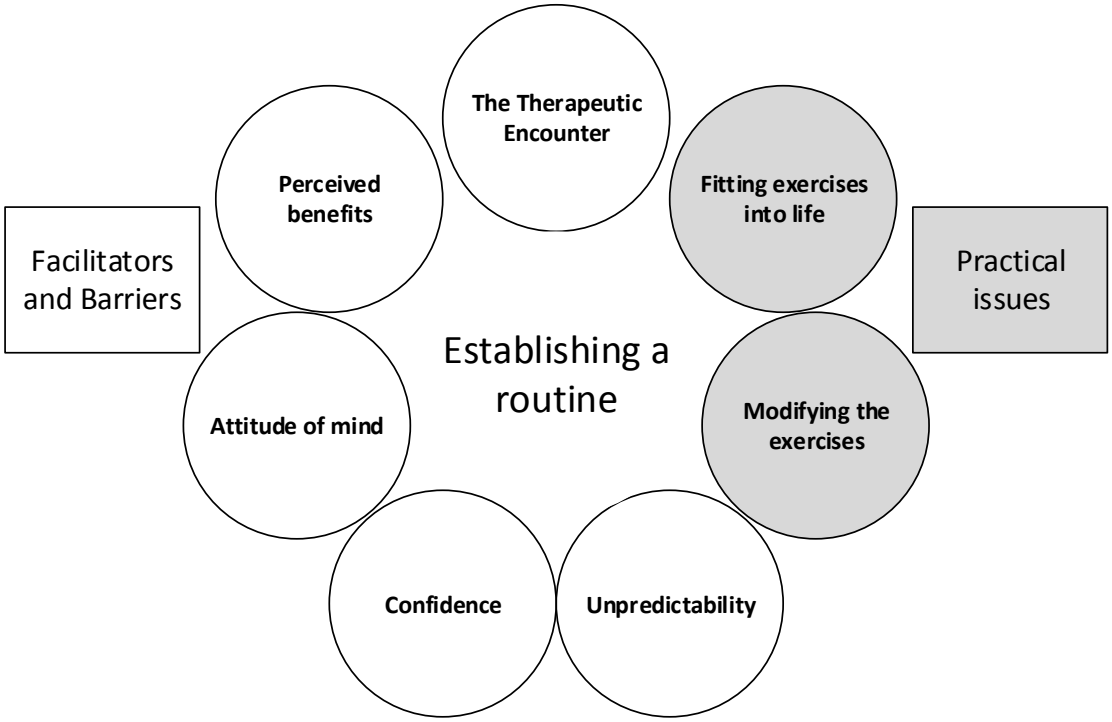
Methodological issues

A limitation of this study was that it was conducted within the context of a clinical trial so may not apply to patients in clinical settings. The participants had all agreed to participate in an RCT of exercises so may have been more likely to comply with an exercise programme than patients seen in everyday clinical practice. Also, we had planned to interview up to 10 participants who reported that they had not benefited from the exercise progamme but we were only able to identify 4 participants fulfilling this criteria. Therefore, the majority of participants had benefited from the programme which may introduced bias. A strength of

this study is that we have been able to study exercise adherence over time and not just at one point to capture the changing nature of RA and life itself. Another strength of this study is that we endeavoured to ensure rigour in our methods. We made sure data was accurate by checking transcripts against interview recordings. Three members of the study team examined the emergent themes to ensure the data was interpreted appropriately and the themes were valid. The researchers conducting the interviews were not involved in delivering the interventions and encouraged participants to share their experiences freely. Open ended questions were used to allow the participicant to guide the discussion and cover things we did not anticipate. We took notes to aid reflexivity. Despite the limitations described, we are confident that our study gives insight into the experience of individuals trying to exercise alongside RA and provides information to aid clinicians implement the SARAH programme into clinical practice.

CONCLUSIONS

Understanding the experiences of participants who successfully adhered to the SARAH exercise programme can assist with implementation of the clinically and cost effective SARAH exercise programme. Establishing a routine during therapist sessions promoted independent exercise during the unsupervised phase. The flexible, individually tailored programme provided these participants with the skills to continue to exercise while dealing with changes in symptoms and schedules. Therapists were integral to this process. Those participants who did not adhere to to the programme provided insight into potential barriers to long term adherence. Therapists need to identify barriers to exercise and assist patients to overcome them when implementing the SARAH exercise programme into clinical practice.


The Therapeutic Encounter
Perceived benefits
Fitting exercises into life
Facilitators and Barriers
Practical issues
Establishing a routine
Attitude of mind
Modifying the exercises
Confidence
Unpredictability

Box 1 Interview schedule – examples of questions

Topic: Living with RA
Can you tell me about the history of your rheumatoid arthritis?
How has having RA affected your life?
How would your life be different if you did not have RA?
How do you see your RA affecting your life in the future?
Topic: Exercising with RA
Are you currently doing any exercise for your RA?
What advice would you give someone with RA about doing exercises?
Has your attitude to exercise changed since taking part in the SARAH trial?
Topic: Participant experience of the SARAH trial
What were you expectations of the treatment that you were going to receive as part of the SARAH trial?
What did you think of the exercise programme?
Was there anything that helped you to do the exercises regularly?
Was there anything that made it difficult for you to do the exercises regularly?
Did the exercise programme work for you?
Why do you think that the exercise programme would work for some and not others?
Would you recommend the programme to other people with RA?
If you ran a programme like this for people with RA what would you change?

Table 1 Interviewee characteristics compared to intervention arm trial participants

	Intervention arm (*n*=246)	**Interview study (*n*=14)**
Age		
Mean, SD, Range	61.3 (12.4), 27-94	61.4 (11.8), 44-82
Mean years since diagnosis		
Mean, SD, Range	13.1 (10.7), 0-43	13.2 (11.9), 1-36
Gender		
Males	58 (23.6%)	5 (35.7%)
Females	188 (76.4%)	9 (64.3%)
Ethnicity		
White	238 (96.7%)	14 (100.0%)
Other	8 (3.3%)	-
Marital status		
Single	24 (9.7%)	1 (7.1%)
Married	157 (63.8%)	9 (64.3%)
Separated	4 (1.6%)	-
Divorced	19 (7.7%)	1 (7.1%)
Widowed	28 (11.4%)	3 (21.4%)
Cohabiting	14 (5.7%)	-
Employment status		
Full time employed	29 (11.8%)	2 (14.3%)
Part time employed	26 (10.6%)	2 (14.3%)
Self employed	11 (4.5%)	1 (7.1%)
Unpaid work	3 (1.2%)	-
Unemployed	12 (4.9%)	1 (7.1%)
Looking after home	24 (9.8%)	1 (7.1%)
Retired/inactive	141 (57.3%)	7 (50.0%)
Educational level		
Higher degree	26 (10.9%)	1 (7.1%)
NVQ4/5/degree or equivalent	18 (7.5%)	3 (21.4%)
Higher education below degree	23 (9.6%)	1 (7.1%)
NVQ3/GCE A-level equivalent	18 (7.5%)	1 (7.1%)
NVQ2/GCE O-level equivalent	41 (17.2%)	2 (14.3%)
NVQ1/CSE other grade equivalent	24 (10.0%)	1 (7.1%)
Foreign/other	9 (3.8%)	-
No qualification	80 (33.5%)	5 (35.7%)
(Missing)	7	-
Medication intensity group		
Biologic DMARD therapy	52 (21.1%)	3 (21.4%)
Combination non-biologic DMARD	72 (29.3%)	2 (14.3%)
Single non-biologic DMARD	103 (41.9%)	8 (57.1%)
No DMARD	19 (7.7%)	1 (7.1%)
Hand Function		
Michigan Hand Questionnaire baseline score 0 (worst)-100 (best)	50.7 (16.3) 15-93	58.3 (16.8), 28-88

Legend 1 DMARD = Disease Modifying Antirheumatic Drug

Table 2 Participant adherence to the exercise programme and reasons for not exercising

Participant	Attended exercise sessions[a]	Exercising at 4 months[b]	Reasons for not exercising	Exercising at 12 months[b]	Reasons for not exercising
Kate	4/6	Yes		Yes	
Harry	5/6	Yes		Yes	
Alice	All	Yes		Yes	
Joe	All	Yes		Yes	
Samantha	All	Yes		Yes	
Mark	All	Yes		Yes	
Sadler	All	Yes		Yes	
Lucy *age 64* *21 ysd*	All	Yes		No	*"…my RA decided to flare up. And it has been the same since. My hands are… and I have stopped doing the exercises because my hands were just too sore."*
Bert *age 62* *29.5 ysd*	All	Yes		No	*"I have always said from the beginning that my hands were very, very good. It was a drag and I couldn't see any possible benefit."*
Lizzy *age 59* *8mths sd*	All	Yes		No	*"…then her passing away and then for the next week it was such a lot to do... I totally forgot for a whole fortnight ...an emotional journey I was having that had triggered, made things worse…and then with having the flare up, it's just….gone. "*
Sally	All	Yes		N/A	Declined 2nd interview
Susan *age 60* *35 ysd*	All	No	*"... because the flare-up, it just... You know, everything just stopped."*	No	Same as 4 months
Emily *age 82* *8ysd*	All	No	*"I was trying to catch up in the garden and do things in the garden and all of a sudden I was trying to do things in the house I hadn't done for a while and the exercises sort of got put by the wayside and I thought well, at least I'm exercising doing things, so I didn't worry too much."*	No	*"I keep thinking, right I ought to try those exercises again now, and I'm sure I will, but as I say, the pain of my shoulder, it really puts you off doing anything."*
Jean *age 81* *4 ysd*	3/6	No	*"I didn't see any point really, because not only were my fingers feeling absolutely great and my hands were, but I was so busy with those (sugar paste) flowers."*	No	Same as 4 months

[a] Based on treating therapist's report; [b] Reported by participant ysd=years since diagnosis

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Declaration of Interest

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